Medical Xpress

Endometriosis takes almost a decade to be diagnosed in the UK. Research reveals some of the reasons why

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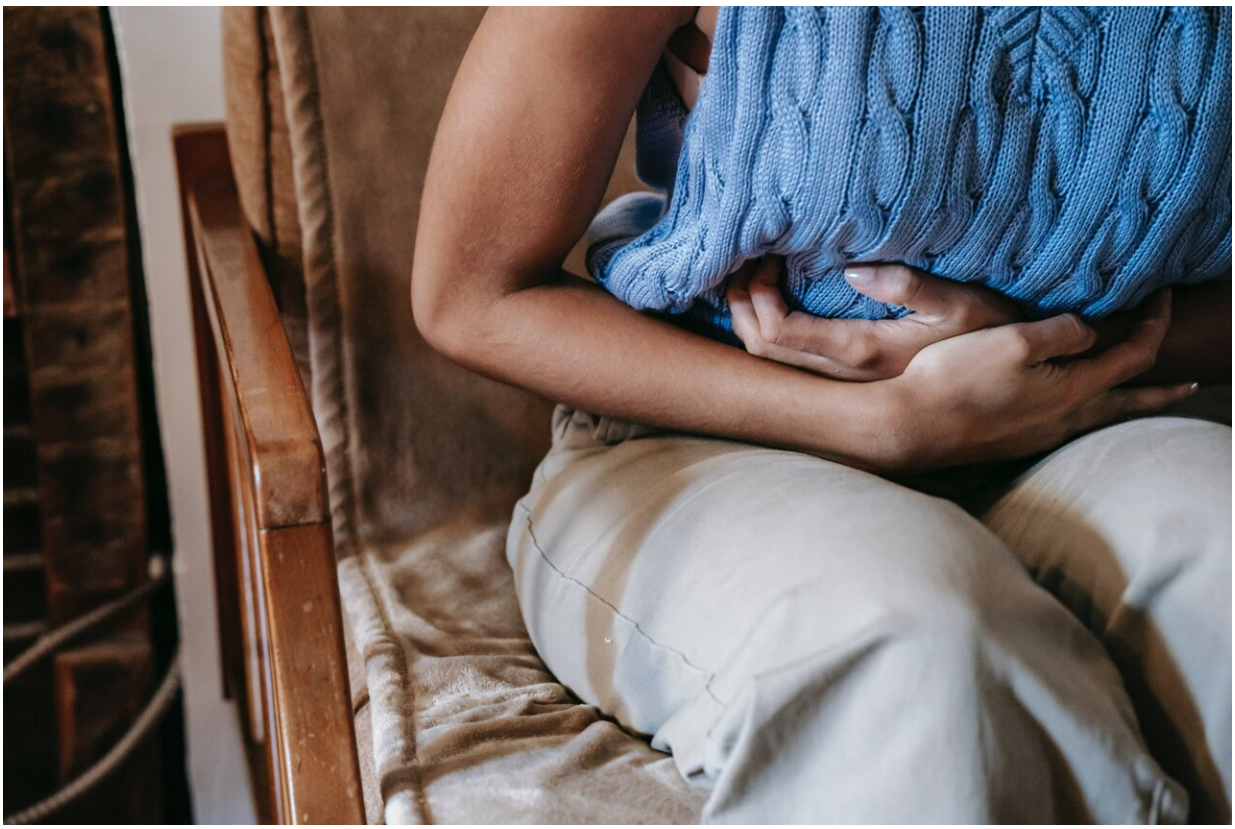

Credit: Sora Shimazaki from Pexels

Around 1 in 10 women and people with uteruses in the UK have endometriosis. This disease causes tissue similar to the womb's lining to

grow in other places—such as the ovaries and fallopian tubes. This can cause chronic pain, difficulty getting pregnant, organ damage and fatigue.

Yet despite how common endometriosis is, people who have the disease still wait around eight years on average to be diagnosed.

There are numerous, complex reasons for this delay. A lack of knowledge about endometriosis by both those affected and health care professionals has been suggested, meaning those with symptoms may not know to ask for help—and those that do may receive poor quality care.

We wanted to better understand what barriers people continue to face when it comes to endometriosis care. We used interviews and an open-ended online survey to learn about these experiences.

A total of 33 women completed the online survey—21 of whom were diagnosed with endometriosis, and 12 who were seeking a diagnosis. We also conducted in-depth interviews with four of the women who have been diagnosed with endometriosis.

Our research identified the four main challenges people faced in accessing endometriosis care:

1. Systemic sexism

Our participants described a health system tarred by systemic sexism. Experiences were characterized by doctors and nurses not believing them or thinking they were exaggerating.

One participant said, "I have been told that my pain was in my head or that I must have a low pain threshold."

This led the participants to feel ashamed, embarrassed and powerless—making them less likely to seek out help in the future.

Many also reported feeling their concerns were dismissed as "women's issues" that shouldn't be discussed, with one interviewee revealing:

"I have no problem talking about menstruation and periods—but it is people's and society's reactions to the topic that makes me feel as though I cannot say anything. Almost as if it is a women's issue that you must deal with quietly and alone."

This also extended to their workplace, where some reported not being supported by management even after being diagnosed—and feeling pressure to return to work early after surgery.

2. Long waiting lists

Long waiting lists prevented participants from seeking help. And, many felt resigned to pay for private health care if they could afford it. Those who couldn't were left "in the hands of the NHS."

Nine participants reported paying for private tests or appointments. These participants saw this as the only way to get a diagnosis, with one interviewee revealing:

"When I raised endometriosis as a potential issue I was given the reply 'I don't know anything about that condition' from the GP. Non-specialist gynecologists also seem to misunderstand the condition and it was only when I recently went for a private consultation that I was believed and was told it's highly likely that I have the condition."

Others chose private care because they felt waiting any longer for NHS care would have had a serious impact on their mental health.

3. Lack of treatment options

Participants overwhelmingly reported they felt helpless about their treatment options—even after being diagnosed. As one interviewee put it:

"I feel helpless when I try to manage my pain. I feel overwhelmed and I can sit there for a while and just not know what to do. I feel like I have given up trying to manage my pain. I've noticed it has become part of my life and I am used to it, to the point where I don't notice the mild discomfort anymore. I don't think I even realized that a healthy person doesn't have this constant pain."

Others reported this helplessness stemmed from their experiences with health care providers. One participant even said her doctor made her feel that "surgery was pointless"—revealing that when she was offered surgery, she was told it would have little effect in managing her pain.

Another participant stated that the "general 'trial and error' approach to my treatment made me feel mistrusting of the diagnosis process and subsequent treatment."

4. Self doubt and fatigue

Having symptoms repeatedly dismissed and not believed by doctors led women to mistrust their own experience. They worried that even if they tried getting help, they wouldn't receive the support they wanted anyway. Women reported intense and overwhelming fear and helplessness, feeling drained from being forced to advocate for themselves.

One woman told us, "I have totally lost faith in my own thoughts and feelings and feel genuinely terrified to try and speak to more doctors."

Another said, "I don't have it in me to fight and advocate for myself anymore as it's just so exhausting."

Need for change

Having strong, trusting relationships with doctors is central to having a positive experience in managing endometriosis and getting the right health care. When concerns are repeatedly dismissed, it can cause people with endometriosis to avoid engaging with the health care system altogether. Our research shows that these issues still remain problems today, contributing to delayed diagnosis and poor management of the disease.

Our findings suggest that we need cultural change. We need to de-stigmatize gynecological health and change attitudes towards pain so that it's no longer dismissed or normalized.

We also need better awareness of endometriosis and training for doctors and nurses so that diagnoses and treatment happen more quickly.

But until that systemic change happens, many people with endometriosis may still face obstacles in accessing care. If you suspect you have endometriosis, we advise keeping a "pain diary"—documenting when, where and how often your pain is happening so that you can provide your doctor with more detail on your experiences.

If you don't feel like you're being taken seriously, ask for a second opinion. There's also lots of support available from national charities such as Endometriosis UK, which can provide information on the condition, and also offer support groups and helplines for those affected.

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